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ABSTRACT

This final report describes major activities and outcomes of a one-year project in Birmingham, Alabama, which attempted to utilize quantitative record linkage methodology and a qualitative family interview to increase the available information regarding risk factors associated with special education placement for young children. The project involved identification of the special education population and random selection of first grade general education students; a computerized retrospective data linkage, linkage of Alabama birth certificate data and Child Count data; qualitative interviews with 42 parents of children in general education and 92 parents of children in special education; development of risk profiles for special education placement; and dissemination of information to local and state early intervention and special education officials. Appendices include the data sharing agreement, the training protocol for training interviewers, the family interview protocol, and results of case control analysis. (DB)

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ED 418 540

Student Initiated Research

Early Identification of Children at Risk for Special Education Placement

Final Progress Report for
PR/Award Number H023B60002
Funding period 09/01/96 - 8/30/97

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The University of Alabama at Birmingham
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FINAL PROGRESS REPORT
Early Identification of Children at Risk for Special Education Placement
For 09/01/96 - 8/30/97

MAJOR ACTIVITIES AND ACCOMPLISHMENTS

The major activities, intended outcomes, evaluation method or criteria for success, the revised timeline for accomplishment of activities, the actual outcomes, and the project's perceived level of success with that activity are listed on the following chart, Early Identification Outcomes (See Table 1). The goals, activities, and accomplishments are detailed in the narrative below.

OVERALL PROJECT GOAL

Utilized quantitative record linkage methodology and a qualitative family interview to increase available information regard risk factors that are associated with special education placement.

Objective 1: To identify the special education population (including all categories of exceptionality) and randomly select a sample of general education students and their families.

Activity 1.1. Contact AL State Dept of Education, Division of Special Education for an official count of number of children in first grade special education in 1995-1996 school year in Birmingham City LEA (B'ham LEA). *Status: Completed.* The Alabama State Dept of Education, Division of Special Education was very cooperative in providing the necessary information regarding children in first grade special education.

Activity 1.2. Contact AL State Dept of Education for an official count of number of children in first grade general Ed in 1995-1996 school year in B'ham LEA. *Status: Completed.* The Alabama State Dept of Education was very cooperative in providing the necessary information regarding children in first grade general education, although this information was not available in computerized format.

Activity 1.3. Contact and approval of B'ham LEA officials for their cooperation to distribute parental/guardian informed consent forms. *Status: Completed.* After initial reservations on the part of the school system officials, an agreement was reached with the Birmingham City LEA officials. After the agreement was reached, they were very cooperative in distributing parental informed consent forms. Due to initial reservations by school officials, this process took longer than expected.

Activity 1.4 Obtaining a de-identified list of general education children from which

a random sample will be selected. *Status: Completed.* This information was obtained, yet it was not available in computerized form. The information given to researchers was then entered into a computer program by research assistance for ease of sampling later.

Activity 1.5 LEA distribution of informed consent forms to selected sample of general education children and their families and all special education children and their families. *Status: Completed.* This area proved problematic, although the school system was cooperative in distribution of letters, some issues remained. Due to confidentiality, special education names were not released, therefore, only an approximate number of forms for children in special education could be given to schools. Thus, there was little control over who received these letters.

Activity 1.6 LEA re-distribution of informed consent forms to further encourage participation. *Status: Completed.* The Birmingham City LEA re- distributed parental consent form in a timely and cooperative manner.

Objective 2: To conduct the computerized retrospective data linkage, linking Alabama birth certificate data and Child Count Data.

Activity 2.1a. Obtain permission for access to all necessary information and resources from Department of Public Health and Department of Education. *Status: Completed.*

Activity 2.1b. Obtain data file of children in first grade special education in 1995-1996 school year in B'ham LEA from AL State Dept of Ed, Division of Special Education. *Status: Completed.* See Data Sharing Agreement - Appendix A.

Activity 2.2 Obtain data file of all birth cohorts (1988-1990) of children in first grade special education in 1995-1996 school year. *Status: Completed.* See Data Sharing Agreement - Appendix A.

Activity 2.3 Enlist cooperation of Dept of Public Health officials and use of computer facilities for data linking procedures. *Status: Completed.* This process was delayed for a short period due to the Department of Public Health moving locations, yet plans for use of their computer facilities were made and carried out.

Activity 2.4 Updating data linkage and case-control programs from pilot phase of Project Early ID. *Status: Completed.* This work was done in conjunction with the actual data linkage.

Activity 2.5 Conduct actual data linkage between birth certificate data and special education data. *Status: Completed.* Data linkage was conducted in a timely matter, with few setbacks. In 4 trips to the Alabama Department of Public Health facilities, data linkage was completed on 161 out of 207 records for a match rate of 78%.

These matches were subsequently checked by hand for accuracy, which resulted in a correct match rate of 99%, with all but one record matched correctly.

Activity 2.6 Conduct case-control program analysis with establishment of 2 control subjects based on age, gender, and ethnicity within B'ham LEA for each matched case from birth certificate and special education matched data file. *Status: Completed.* This activity was revised slightly. Instead of using 2 controls subjects, 5 control subjects were located and used for each case. This greater number of controls was used to ensure a large sample size in the family interview phase of the project.

Objective 3: To conduct qualitative interviews with parents of children in general and special education.

Activity 3.1 Recruit and train research assistants to conduct interviews. *Status: Completed.* Recruited and trained a total of 17 research assistants/interviewers. This group included African American students, and 2 persons with disabilities (i.e., cerebral palsy, hearing impairment). Further, one student interviewer has a sibling with a disability (i.e., Down Syndrome). The student interviewers were trained with a specific training protocol (See Appendix B). In addition, Mr. T. Hyche, Special Education coordinator with the Birmingham City Schools provided training on working with lower income families within the Birmingham LEA.

Activity 3.2 Set up interview stations with telephones and other necessary equipment. *Status: Completed.*

Activity 3.3 Obtain informed consent from participating families, both children in special education and children in general education. *Status: Completed.* We attempted to conduct 421 family interviews from special and general education families. Of this group, a total of 166 consent forms were completed and interviews attempted. See Appendix C for copy of family interview.

Activity 3.4 Schedule interview times. *Status: Completed.* Some family interview times were easily scheduled and informants easily reached, with a minimum number of phone calls (1-2 times). Yet, some interviewees were very hard to reach and had to be called multiple times (6-10 times). Despite repeated calls, multiple appointments had to set up for some, because the respondent would not be at home when he/she was called back.

Activity 3.5 Contact and conduct family interviews with all consenting families, by telephone or in person. *Status: Completed.* A total of 141 interviews were completed, out of the 166 informed consent cards received. Of these, 92 were families of special education students, and 49 were families of general education children. The reasons interviews were not completed are :

Reason	N	Percent
Parent refused Interview	11	6.6
Non working number	3	1.8
No answer (6-10 attempts)	4	2.4
No eligible respondent at number	4	2.4
Interview terminated within questionnaire (*partial data recorded)	3	1.8

Activity 3.6 Data entry of family interview. *Status: Completed.* Data entry was completed in a timely fashion. Data was entered and double checked for accuracy, and any discrepancies resolved. Data was entered in Excel spreadsheet software, and later converted to SAS for statistical analysis.

Activity 3.7 Develop quality assurance control. *Status: Completed.* For over 50% of interviews, reliability was determined. This process involved the interviewer and reliability interviewer reviewing data immediately after the interview was conducted (the reliability interviewer listened to the interview on another phone), discrepancies were resolved, and families contacted again, if necessary. Overall, reliability estimates were averaged to be 97%.

Activity 3.8 Establish data linkage file linking original birth certificate/special education file with family interview information. *Status: Completed.* This task proved to be harder than expected and was not as successful as desired. Researchers were able to establish a linked file with the family interview and birth certificate/special education file. Yet, the number of family interviews which was linked to the linked birth/school record was small. More specifically, only 84 of the 166 original interviews attempted were able to be matched using a series of matching steps. Thirty Five percent of special education subjects and 77% of general education subjects family interviewers were able to be successfully linked and part of the data set that had all 3 pieces of data (birth record, school record, and family interview).

Objective 4: To develop risk profiles for special education placement.

Activity 4.1 Calculation of odds ratio for variables from birth certificate. *Status: Completed.* Calculated odds ratios which showed maternal education (Odds Ratio = 6.4, $p < .05$) and Apgar scores (Odds Ratio = 3.9, $p < .05$) were most predictive of special education placement, specifically in mental retardation category (See Appendix D).

Activity 4.2 Calculation of odds ratio for all critical variables from family interview. *Status: Not Completed, in progress.*

Activity 4.3 Conduct descriptive statistics for all critical variables from family interview. *Status: Completed.* For a sampling of descriptive statistics, see Table 2.

Activity 4.4 Compare critical variables from family interview between families with children in special education and families with children in general education. *Status: Not completed, in progress.*

Activity 4.5 Based on odds ratios obtained from Activities 4.1 and 4.2, development of risk profiles of high, medium, and low risk for placement in special education. *Status: Not completed, in progress.*

Objective 5: To disseminate information to the local and state early intervention and special education officials for practical implementation.

Activity 5.1 Contact local and state officials to secure commitment for later meetings and dissemination of findings to all interested parties. *Status: Revised and Completed.* Initial contact made with local and state officials, and members of Technical Advisory Committee were met with to discussion project and implementation. Subsequent meetings and discussions were on informal basis as deemed necessary.

Activity 5.2 Bimonthly meetings of Technical Advisory Panel. *Status: Schedule Revised and Completed.* Convened Technical Advisory Committee for discussion and trouble shooting session at beginning of project. All subsequent discussions of issues or concerns were on informal basis individually with members of the Technical Advisory Panel, as needed.

Activity 5.3 Bimonthly written report of progress for local and state officials tailored to the needs of local and state agencies. *Status: Revised goal based on need.* It was determined that bimonthly written progress reports were not necessary nor desired by state and local officially. All information was provided as information was requested by agencies.

Activity 5.4 Final report for local and state officials as well as granting agency tailored to the needs of local and state agencies. *Status: Not Completed, in progress.* Final report for granting agency is completed. Final report for local and state officials will be a revised version of the final report for the granting agency, and is in progress of being completed.

Activity 5.5 Final meeting upon completion of investigation to inform all participating teachers, parents/guardians, LEA officials, and state officials. *Status: Not Completed, To be Scheduled.*

Table 1
Early Identification Project Outcomes

Objective 1: To identify the special education population (including all categories of exceptionality) and randomly select a sample of general education students and their families.

Activities	Intended Outcome	Evaluation Method/ Criteria for Success	Revised Time frame	Actual Outcome	Level of Success
1.1 Contact AL State Dept of Ed, Division of Special Education for an official count of number of children in first grade special Ed in 1995-1996 school year in Birmingham City LEA (B'ham LEA)	Obtaining receipt of official count	Computer printout of number of children in B'ham LEA. Reported by special education classification and school	10/ 96	Received official count of number of children in first grade special Ed in 1995-1996 school year in Birmingham City LEA (B'ham LEA)	High
1.2 Contact AL State Dept of Ed for an official count of number of children in first grade general Ed in 1995-1996 school year in B'ham LEA	Obtaining receipt of official count	Computer printout of number of children in B'ham LEA. Reported by school	10/ 96 - 11/96	Received official count of number of children in first grade general Ed in 1995-1996 school year in Birmingham City LEA (B'ham LEA)	High
1.3 Contact and approval of B'ham LEA officials for their cooperation to distribute parental/guardian informed consent forms	Cooperation of B'ham LEA officials and teachers	Written statement - investigators and B'ham LEA officials specifying agreed upon issues	10/ 96 - 1/97	After several meetings with school officials, gained approval for distribution of consent forms	Medium
1.4 Obtaining a de-identified list of general education children from which a random sample will be selected	List of students by code number	Selection of randomly selected children from general education population	11/ 96 - 12/96	Obtained list of general education children from which a random sample was	High
1.5 LEA distribution of informed consent forms to selected sample of general Ed children and their families and all special Ed children and their families	Receipt of consent forms from willing participants	Written and verbal confirmation of date of consent form distribution	12/ 96 - 3/97	After several meetings with school officials, gained approval for distribution of consent forms, yet approval date was later than had planned	Medium
1.6 LEA re-distribution of informed consent forms to further encourage participation	Receipt of consent forms from willing participants	Written and verbal confirmation of date of consent form distribution	1/ 97 - 3/97	LEA re distributed letters to parents	High

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Objective 2: To conduct the computerized retrospective data linkage, linking Alabama birth certificate data and Child Count Data.

Activities	Intended Outcome	Evaluation Method/ Criteria for Success	Revised Time frame	Actual Outcome	Level of Success
2.1 Obtain permission for access to all necessary information and resources from Department of Public Health and Department of Education	**Agreement among Dept of Public Health, Dept of Ed and Civitan Center**	**Written statement specifying agreement among Dept of Public Health, Dept of Ed and Civitan Center**	**9/ 96 - 10/96**	**Was able to gain access to information from Department of Education and Department of Public Health**	**High**
2.1 Obtain data file of children in first grade special education in 1995-1996 school year in B'ham LEA from AL State Dept of Ed, Division of Special Ed	**Obtaining access to data file**	**Computer printout of available variables**	**9/ 96 - 11/96**	**Obtained data file of first grade children**	**High**
2.2 Obtain data file of all birth cohorts (1988-1990) of children in first grade special education in 1995-1996 school year	**Obtaining access to data from state computer facilities**	**Computer printout of available variables**	**9/ 96 - 10/96**	**Obtained data file (not hard copy) of birth records**	**High**
2.3 Enlist cooperation of Dept of Public Health officials and use of computer facilities for data linking procedures	**Cooperation of Dept of Public Health director and data analysis supervisor**	**Written statement between investigators and Dept of Public Health officials specifying agreed upon issues**	**9/ 96 - 10/96**	**Informal verbal agreement for use of computer facilities in conjunction with their schedules. Some delay due to the DPH moving buildings**	**Medium**
2.4 Updating data linkage and case-control programs from pilot phase of Project Early ID	**Update of birth cohorts and control match variables**	**Outline of current data linkage steps and printout of actual statistical program**	**10/ 96 - 2/97**	**Update data linkage and case control programs**	**High**
2.5 Conduct actual data linkage between birth certificate data and special education data	**Final data set with matched cases**	**Computer printout of available variables and cases**	**10/ 96 - 2/97**	**Successful data linkage between birth and school records, although later than expected**	**Medium**
2.6 Conduct case-control program analysis with establishment of 2 control subjects based on age, gender, and ethnicity within B'ham LEA for each matched case from birth certificate and special education matched data file	**Final data set with matched cases and controls**	**Computer printout of available variables and cases and controls**	**1/ 97 - 3/97**	**Successful data linkage between birth and school records and print out of cases and controls**	**High**

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Objective 3: To conduct qualitative interviews with parents of children in general and special education.

Activities	Intended Outcome	Evaluation Method/ Criteria for Success	Revised Time frame	Actual Outcome	Level of Success
3.1 Recruit and train research assistants to conduct interviews.	Recruitment and training of 3-4 interviewers	Appropriately trained to be sensitive to cultural issues and concerns of individuals with disabilities	10/96-11/96	Recruited and trained 17 research assistants; trained in cultural sensitivity, included African American interviewers and 2 persons with disabilities, trained by Special Education Coordinator within Birmingham City Schools about working with these families	High
3.2 Set up interview stations with telephones and other necessary equipment.	3-4 separate desks within a central location	Availability of interviewers to supervisor	11/96-12/96	Able to set up interviewers' work station	High
3.3 Obtain informed consent from participating families, both children in special education and children in general education	Receipt of consent forms from willing participants	Assignment of a family code to each participating family	11/96-3/97	Was not able to achieve informed consent from as high a percentage of sample as was desired; interviewed approximately 50% of special education sample, yet a low percentage (20%) of general ed. families	Low- Medium
3.4 Schedule interview times	To effectively manage time and coordinate interviewers	An agreed upon schedule	11/96-6/97	Some interview times were easily scheduled and informants easily reached, yet some interviewees were very hard to reach and had to be called multiple times and multiple appointments set up	Low- Medium
3.5 Contact and conduct family interviews with all consenting families, by telephone or in person	Completion of interviews with all willing participants	Creation and completion of codes for classifying status of interviews	12/97-6/97	Some interview times were easily scheduled and informants easily reached, yet some interviewees were very hard to reach and had to be called multiple times and multiple appointments set up	Low- Medium
3.6 Data entry of family interview	Reliable and efficient data entry	Documentation of and correction of discrepancies between doubly entered data	1/97-6/97	Entered and Double entered all data, discrepancies were resolved, and families contacted again if necessary	High
3.7 Develop quality assurance control	Reliability among interviewers	Percent reliability among interviewers	11/96-6/97	Over 50% of interviews, interviewer and reliability interviewer reviewed data, discrepancies were resolved, and families contacted again if necessary	High
3.8 Establish data linkage file linking original birth certificate/special education file with family interview information	Merge family interview data set with original data linkage file	Final data linkage file and computer printout of available variables and number of cases	5/97-7/97	Was able to establish file with interview and birth certificate/special education file, yet only for a small percentage of subjects (N=84; 35% of special education subjects and 77% of general education subjects)	Low

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Objective 4: To develop risk profiles for special education placement.

Activities	Intended Outcome	Evaluation Method/ Criteria for Success	Revised Time frame	Actual Outcome	Level of Success
4.1 Calculation of odds ratio for all variables from birth certificate	**Gather relevant information for most parsimonious risk profiles**	**Determine which variables are predictive of later special education placement**	**6/97**	**Calculated odds ratios which showed maternal education and Apgar scores were most predictive of special education placemen, specifically in mental retardation category.**	**High**
4.2 Calculation of odds ratio for all critical variables from family interview	**Gather relevant information for most parsimonious risk profiles**	**Determine which variables are predictive of later special education placement**	ongoing	**Due to small number of family interviews linked back to original birth/school data, this has not yet been successful.**	Low
4.3 Conduct descriptive statistics (frequencies, means, medians, etc.) for all critical variables from family interview	**Provide results for dissemination and practical implementation (see Objective 5)**	**Communication and dissemination of findings to appropriate individuals**	ongoing	**Descriptive statistics conducted.**	High
4.4 Compare critical variables from family interview between families with children in special education and families with children in general education	**Evaluation of potential differences between special education and general education groups**	**Explanation and interpretation of potential differences to provide clearer understanding of special education placement**	ongoing	**Due to small number of family interviews linked back to original birth/school data, this has not yet been successful.**	Low
4.5 Based on odds ratios obtained from Activities 4.1 and 4.2, development of risk profiles of high, medium, and low risk for placement in special education	**Establish and describe risk profiles**	**Ensure that risk profiles are appropriate for implementation**	ongoing	**Due to small number of family interviews linked back to original birth/school data, this has not yet been successful.**	Low

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Objective 5: To disseminate information to the local and state early intervention and special education officials for practical implementation.

Activities	Intended Outcome	Evaluation Method/ Criteria for Success	Revised Time frame	Actual Outcome	Level of Success
5.1 Contact local and state officials to secure commitment for later meetings and dissemination of findings to all interested parties	Inclusion of all appropriate and necessary individuals	Written support from committed, interested individuals	11/97-ongoing	Initial contact made, members of Technical Advisory Committee were met with; other meetings and discussions were on informal basis	Low
5.2 Bimonthly meetings of Technical Advisory Panel	Discussion of critical issues and update of progress of investigation	Summary of issues discussed during these meetings	Sept 96, Nov 96	Convened Technical Advisory Committee for discussion; subsequent discussions were on informal basis	Medium
5.3 Bimonthly written report of progress for local and state officials tailored to the needs of local and state agencies	Update of progress of investigation	Confirmation of receipt of progress notes	ongoing	Not implemented	Very Low
5.4 Final report for local and state officials as well as granting agency tailored to the needs of local and state agencies	Final summary of findings and recommendations for intervention implementation	Confirmation of receipt of final report	ongoing	In process of drafting final report version for dissemination for state level officials	Medium
5.5 Final meeting upon completion of investigation to inform all participating teachers, parents/guardians, LEA officials, and state officials	Final summary of findings and recommendations for intervention implementation	Completion of feedback questionnaire	ongoing	Not implemented, in process.	Very Low

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Table 2

Descriptive statistics for all critical variables from family interview. (Activity 4.3)

Child Gender	Percent
Boys	65
Girls	35

Child Age	Percent
5 years	22
6 years	60
7 years	17

Interviewee Relationship to Child	Percent
Mother	88
Grandmother	6
Other	6

Marital Status of Interviewee	Percent
Married	38
Never Married	30
Divorced	30

Maternal Education	Percent
No high school	16
High school grad.	33
Some college	24
Associate's Degree	13
College Graduate	6

Maternal Education	Percent
No high school	13
High school grad.	42
Some college	15
Associate's Degree	5
College Graduate	4

Income Level per year	Percent
Less than $5,000	24
$5,000 to $10,000	18
$10,000 to $15,000	13
$15,000 to $20,000	10
$20,000 to $25,000	9
Above $25,000	26

Did child receive Early Intervention?	Percent
Yes	24
No	75

Appendix
A

MEMORANDUM OF UNDERSTANDING
BETWEEN THE
DEPARTMENT OF PUBLIC HEALTH, DEPARTMENT OF MENTAL HEALTH AND MENTAL RETARDATION, DEPARTMENT OF EDUCATION, AND THE CIVITAN INTERNATIONAL RESEARCH CENTER

1. Purpose: The purpose of this memorandum of understanding is to provide the framework for an interagency arrangement for the development, maintenance, and use of a data sharing procedure to be used for an epidemiological surveillance program targeted at mental retardation and other developmental disabilities.

2. Basis: A state capacity building grant from the Center for Disease Control and Prevention that was awarded to the state of Alabama beginning in October 1992 requires the development of an interagency epidemiological surveillance system that targets four disorders: mental retardation associated with low socioeconomic status, secondary disabilities resulting from cerebral palsy, head and spinal cord injuries, and other injury-related disabilities.

3. Scope: The state agencies that will be providing data for the surveillance program include the Department of Mental Health and Mental Retardation, the Department of Public Health and the Department of Education. The primary involvement of the Civitan International Research Center at the University of Alabama at Birmingham will be assisting in data linking and analysis and report preparation. Any other uses of the data are to be approved by the Data Oversight Committee which is described in Section 4 c., below. Data collection and analysis are intended to be used primarily for epidemiological surveillance of mental retardation and secondary disabilities resulting from cerebral palsy. Data sharing directed at other disorders included under the state capacity building grant will be addressed by separate interagency agreement.

4. The parties agree to:

   a. Protect the identity of individuals in all data files and safeguard the security of all information during the data transfer process. Duplicate records will be eliminated, and files will be linked on the basis of a unique identifier that will be created using such information as name, social security number, date of birth, race, and sex since these variables are found to be commonly recorded among the participating agencies' files. Such personally identifiable data will be removed from the combined files as soon as possible after the necessary linking of records and removal of duplicated information have been accomplished. Unique identifiers will be used for authorized analysis only. Under no circumstances will personally identifiable information be made available to the public, researchers, or agencies. Data files will be made available for analysis only after personally identifiable data have been removed.

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b. Transfer data on a schedule to be agreed to later to the Civitan International Research Center where cross-agency duplication removal and file linking will take place.

c. Abide by decisions of a Data Oversight Committee bearing on access to and use of data for research, destruction of data files, and credit for presentations and publications. Membership on the Data Oversight Committee will consist of one representative from each of the reporting agencies to be designated by the agency head. To avoid possible conflicts of interest, the committee will not include members of the MR/DD Prevention Committee or Surveillance Committee. Decisions must be by consensus (i.e., one member may veto).

5. Any agency may withdraw from the project by providing written notification no less than thirty days prior to the date of withdrawal.

6. The parties hereto concur that for purposes of this agreement they shall not be considered an agent of each other party.

Richard E. Hanan
Commissioner
Department of Mental Health
and Mental Retardation

Donald E. Williamson, M.D.
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University of Alabama at Birmingham

Date: August 4, 1993

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Appendix
B

Manual for Standard Interviewing Procedures

Overview

This manual provides information about the fundamentals of interviewing for the purpose of gathering data.

Much of the information contained within these pages will be familiar. Much will seem like common sense. However, a manual like this is important because it provides information for uniform training to all interviewers. Uniform training balances the effect of prior knowledge of interviewing. Read this manual carefully and use the techniques described.

The task of the interviewer is much more complex than it may appear. The interviewer instructs the respondent, gives feedback, models performance, and records data. Figure 12.2 portrays an overview of the interviewer's task and will serve as the outline for this manual. Each of the components will be described separately.

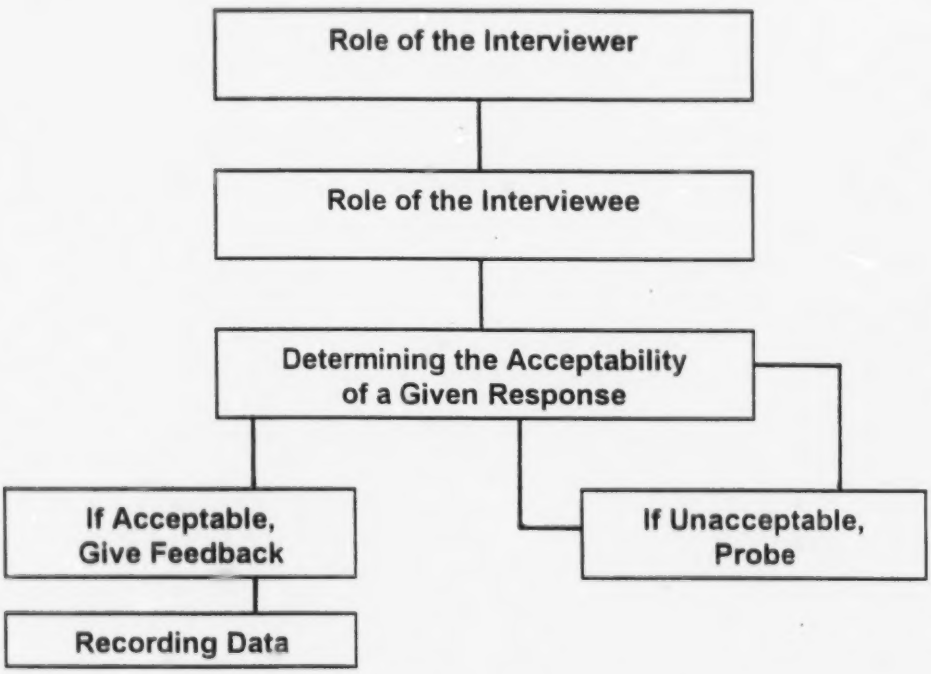
Role of the Interviewer
Role of the Interviewee
Determining the Acceptability of a Given Response
If Acceptable, Give Feedback
If Unacceptable, Probe
Recording Data

Figure 12.2: Overview of Interviewing Techniques

I. The Role of the Interviewer

Interviewing is a form of social interaction, a type of structured conversation. In addition to using everyday social skills, such as tact, attentiveness, and courtesy, an interviewer needs special skills. These special skills include a mastery of interviewing techniques, the ability to remain neutral, and a basic understanding of the goals of a research interview.

Attitude and Manner. Your manner can have a significant impact on the outcome of the interview. Your job is an important one and you should approach it as a professional. Use the tone of your voice to convey your professionalism and self-assurance: express genuine interest in what the interviewee is telling you. Do not approach the questions in an apologetic or embarrassed manner. These questions have been reviewed many times and have not been found to be too personal or offensive. Remember, the job you do is very important to this study. You are our connection to data of good quality.

Neutrality and Confidentiality. In addition to professionalism, tow other attributes are important. These are: 1) the ability to collect data with neutrality, and 2) the maintenance of confidentiality.

Neutrality is important if our data set is to be uncontaminated. The responses of the interviewees are their own. Be very careful to avoid behavior that could affect how they answer. Do not suggest answers, for example, or reword or interpret the question for the interviewees. Do not anticipate an answer to a question. Avoid giving your opinion, even if asked. Do not let your tone or the pace at which you read the questions indicate that one answer is preferable to another. For example, do not read some questions faster or slower than others, or read with vocal infection and others with a monotone.

An interviewee must feel free to speak candidly if you are to gather quality data. In order for a respondent to feel free to speak, complete confidentiality of responses must be established. If you cannot keep confidentiality (such as in case of child abuse), the limits of your confidentiality must be expressed to the respondent before you continue. Preserving confidentiality means: 1) never associating names with the collected data, 2) reporting data using statistical form only, 3) discussing data only with project staff, and 4) conducting interviews as objectively as possible.

Uniformity of Data Collection.. The research interview differs from other types of interviews, because it allows for uniform data collection. To establish uniformity, research interview questions should be read exactly as written. The questions on the interview were written to be neutral, clear, and easily understood by the respondent.

Research has shown that the way a question is worded can have a great impact on the response. All respondents must hear the same question read in the same way; otherwise, the data collected are not comparable across respondents. In addition, all questions should be asked in the same order.

Instructions. Interviewer instructions are written in all capital letters; the part that is read to the respondent is written in both small case and capital letters. Capital letters within parentheses indicate that a substitution is to be made. For example, "How long has (CHILD)...? means that you should substitute the child's name in the sentence, "How long has Jessica ;;;?".

Following skip patterns is one of more complicated tasks of interviewing. Interviews are designed to collect information from many types of people. The skip pattern will enable you to "tailor" the interview to a particular respondent based on data you have already collected. A skip instruction may be associated with a specific question or may be between questions or sections of the questionnaire. Missing a skip instruction may result in the collection of too much or too little data. If there is no skip instruction, you should proceed directly to the next question in the instrument.

Clarification. There will be times when the respondent does not understand the question or asks to have in repeated. Do not reword the question. Instead reread the question as worded, emphasizing parts that she/he may have missed.

If your respondent still has difficulty with an item or word, ask the respondent to interpret the question as best he/or she can. After the interview, please contact the Study Director and let her know about the question the respondent had trouble understanding. Only in this way can we have uniformity.

If the respondent understands but wants clarification of what we mean by a word such as "difficult," do not attempt to define this word. Instead, say "whatever difficult means to you." The respondent's own interpretation of these questions is what we are seeking.

II. The Role of the Interviewee

Training the Respondent to be a Respondent. It is important that you instruct the respondent in how to be a respondent. This is done through modeling, by listening carefully, and by giving the respondent feedback about appropriate responses. Keep in mind that being a respondent is hard work. The respondent must listen carefully to the questions, give complete answers, and provide them in the form used by the questionnaire. For example, learning to fit answers into coded response categories when the most natural answer might be "it depends."

Positive Reinforcement. When the respondent responds appropriately to a question, provide reinforcement. Positive reinforcement can take the form of a word or a gesture to let her know that this the type of behavior you expect. Phrases such as "Yes, I see," "O.K., thank you," "Yes, that's what I meant," are all good examples of positive feedback. You can also reinforce behavior by nodding, smiling and writing sown her comments. How much feedback you use will depend on your respondent. Some learn their role quickly and require only periodic feedback, while others may need to be reinforced every time they make an appropriate response. Be very careful not to reinforce certain types of answers; remember that you are reinforcing behavior, not content.

Digressions and Interruptions. These are some behaviors of respondents that you want to be especially careful not to reinforce. An interview can continue for a very long time if you allow the respondent to tell you a story while answering each question. Often, a respondent thinks that you want a long explanation for every question asked. Learning to keep an interviewee on track is one of the most important skills that you can acquire as an interviewer. A long digression can be halted by saying things such as "That's interesting. Let's finish the interview and then we will talk about this some more." Such a statement not only explains why you are there (i.e., to interview her), but also communicates to her that you are interested in her as a person.

It is important that the respondent hear the entire question and all response categories, when appropriate, before answering. Answers may change after hearing all the possible answer choices. If the respondent tries to answer before you say that he or she needs to hear the entire question before selecting an answer. You also may want to re-read the question.

If an interviewee starts giving you answers to questions that you will be asked later on, say that you will be asking that later. You may also want to say that you have to ask the questions in a certain order. It is better to stop the respondent politely than to have to go through the information twice. You must try to maintain control over the administration of the interview.

Pacing. Pacing is one way in which the interviewer gains control over the interview situation. Establishing a good pace does not mean reading questions in a monotonous fashion. Questions should be read at an approximate rate of two words per second, Do not pause between every word. Instead, you should pause between word phrases.

Researchers have found that the pacing of a question should be slow and even. Respondents will answer more thoughtfully, and you will not have to repeat questions as often. The respondent will set the pace of the interview from information and cues provided by you.

A slower, more leisurely pace will allow you to work carefully and to follow interviewer instructions. Pace can also reduce tension for you and your respondent. As mentioned earlier, slow and even pacing is important because an uneven reading of the question or response categories may bias the respondent by suggesting that some categories are more important than others.

Practice reading the following questions, using the packing marks. Time yourself and see which reading of the item seems more natural.

Pauses between every word:

How-much-does-your-baby-smile-and-make-happy-sounds?

Pause between word phrases:

How much-does your baby-smile-and make-happy sounds?

III. Determining the Acceptability of a Response

The acceptability of a given response is determined by you. In order to make this judgement, the responses must be comprehensible to you. You must also be familiar enough with the question to determine whether or not the respondent answered the question sufficiently.

If the Response Is Acceptable. If the response is acceptable, record the information given and move on to the next question using the given response categories. Be sure that you reinforce the respondent's behavior with a phrase or gesture as described above.

If the Response is Unacceptable. If the response is unacceptable, your first job is to determine why. Often, an answer is unacceptable because it did not answer the question. The respondent may respond with an answer in prose form rather than using one of the precoded response categories. Or the answer may be referring to someone other than the study child, such as another child or a combination of the family's children. The respondent may not have heard the entire question or may not have understood what was being asked. If you determine that this is a possible cause for an unacceptable answer, re-read the question, emphasizing key words that convey the meaning.

Another type of unacceptable response is the digression. It is important not to let a person ramble on. Your job is to re-focus attention on the task at hand. In order to do this either 1) re-read all or part of the question, or 2) ask the respondent to pick an answer category that is closest to what is being described.

Probing for Answers. Frequently, an answer is unacceptable because it does not fit into existing response categories or does not answer specific question. Probing may be needed to re-focus the respondent's attention and with precoded response direction to the available answer choice. For example, you read the available responses and your respondent answers, "it depends" or "somewhere between this category and this one." When the respondent answers in this way, do not just repeat the question. Instead, preface it with an acknowledging remark, such as "which comes closest..." or " in general ..." If the respondent rephrases a response category, do not record the answer that you think comes the closest. Instead, ask the person to select one by saying something like, "Which one of these answers comes closest to yours..." When you re-read the response categories, make sure that you read all the available choices. You do not want to narrow the choice for the respondent by reading only the choices that are closest to the original statement. By probing in the ways described above, you continue to train the interviewee to be a respondent.

A response of "I don't know" is one that should be probed. "I don't know" is the response that requires the least amount of thought on the part of the respondent. A "don't know" can mean several things. It can mean that the respondent has never thought about the issue. Or the person may think that you are not expecting a thoughtful answer to a question. In this case, the best probe is the silent probe. Simply wait expectantly for an answer. With this type of probing, you are communicating to the respondent that you expect an answer to this question and that the "don't know" response was a preface to her answer. If your silent probe does not communicate your expectation for an answer, you may try answering the "don't know" with "I wonder if you can take a minute or two to think about it."

A respondent's "don't know" may also mean that he or she genuinely does not have an answer to the question. If this is the case, record the "don't know" answer and go on to the next question. To be certain that your respondent's "don't know" fits into this category, probe all "don't know" answers is not to force an answer if the respondent does not know the answer, but rather to give a chance to think about the response.

To summarize, if a respondent's answer is unacceptable for the response of data collection, you must follow three steps:

1) Determine why the answer is unacceptable.

2) Provide feedback by re-reading the question, by stopping a digression, or by re-focusing attention on the meaning of the question.

3) Record and reinforce the answer when it is acceptable.

IV. Recording Data

The final step in the interviewing process is recording the data collected. As with all steps of the interview, please follow the rules and guidelines carefully in order to endure the collection of uniform data.

Recording Answers. When recording the information into the interview form, always use a black pen. This color photocopies will and allows other colors, such as red or green, to be reserved for office use only. Record all answers neatly and legibly.

You may want to make notes to yourself or to the Project Director during the course of your interview. It is important that you distinguish between these notes and statements by the respondent. Circle notes made to yourself and enclose notes to the Director parenthesis. This will enable the data processing staff to distinguish at a glance between your notes and statements made by the respondent.

**You should always bring a tablet of paper with you when you are interviewing. You may need more space to record an answer than the space available on the interview form. Write extra information or your comments in the left margin. If you need more room, attach an extra sheet of paper to the form.

Editing. Before you turn in your interview form, carefully proofread the entire interview. Pay particular attention to the legibility of responses and whether or not the interviewer's instructions were followed.

Even with careful checking of your interview booklet, it is possible to overlook an item. If this happens, do not try to recall what the respondent said. Instead, record "omitted in error." You may want to try to recontact the respondent to retrieve the missing information.

If the respondent changes her mind or if you asked a question that you should not have asked, cross the information out with a single line and record R.E. (respondent's error) or M.E. (My error). In no case should you try to erase information that you have already recorded.

Make sure each response is legible by clarifying unclear handwriting. Spell out all abbreviations.

**You will need to listen to the audiotape of the interview and fill in any portions that were not complete during the interview.

Summary

In conclusion, the task of the interviewer is quite complex; it requires excellent social and listening skills. It also requires that you act as instructor, teaching the respondent a new and different task, and giving her feedback, accordingly. Finally, it requires that you act as a scientist, gathering data for a research study. In order to carry out the best research study possible, we are depending on you to do your job well.

Interviewing Practice Exercises

This section will allow you to practice the skills you have just finished reading about. Each exercise will emphasize a different type of interviewer skill. Try to answer each question listed as per the specifications of this section of the manual. The answers follow.

Exercise 1:

Interviewer: Thinking about Sarah during the last two weeks, did she eat well, rarely or never, some of the time, or almost always?

Respondent: I don't know. She responds well to new foods. She'll eat almost anything. But she doesn't eat a lot.

Interviewer: Fill in response here.

Exercise 2:

Interviewer: Thinking about Michael, during the last two weeks, did he sleep well, rarely or never, some of the time, or almost always.

Respondent: What do you mean by "sleeping well?" Do you mean does he sleep a lot or sleep soundly?

Interviewer: Fill in response here.

Exercise 3:

Interviewer: In the past four months has she taken antibiotics?

Respondent: I don't know.

Interviewer: Silent probe.

Respondent: I don't think I understand the question.

Interviewer: Fill in answer here.

Exercise 4:

Interviewer: Compared to most children Marsha's age, that is, 15 months old, would you say she is developing faster than other children, about the same as other children, slower than other children, or much slower than other children?

Respondent: I don't know

Interviewer: List steps for probing this answer.

Answers to Interviewing Practice Exercises:

Exercise 1. The goal of this exercise is to provide practice in evaluating respondent's answer. She has not answered the question. When you get an answer such as this one, re-read the question emphasizing the words that will help her arrive at an answer. In this case, indicate that she is to consider "eating well" in general and emphasize the phrase "during the last two weeks." Then re-read the response categories.

Exercise 2. In this case, the respondent appears to under the question. However, she wants clarification of a common phrase which can have several interpretations. You should respond with "whatever sleeping well means to you."

Exercise 3. There are several specific steps that you should go through before recording an answer of "I don't know." You should first use the silent probe, i.e., wait expectantly for an answer. This will give your respondent a chance to think about her answer. If she still does not answer, tell her we are just interested in her opinion. Then, re-read the question, emphasizing key words or phrases. If the respondent is still unable to answer your question, record "don't know" and go to the next question.

Appendix
C

EARLY CHILDHOOD PROJECT PARENT TELEPHONE SURVEY
SPECIAL EDUCATION CHILDREN

If this was an Interview with RELIABILITY completed.... Is this copy: the **Main Interviewer Copy** _____ or the **Reliability Interviewer Copy** _____

NOTE: ON MAIN INTERVIEWERS' COPY OF INTERVIEW, DO NOT ERASE, BUT MARK AGREED UPON ANSWER ON BOTH INTERVIEWS CLEARLY (I.E., ANOTHER COLOR PEN)

Reliability _____ **%**

SUBJECT ID: _____
INTERVIEWER ID: _____

CHILD'S First NAME: _____
CHILD'S Middle NAME or initial: _____
CHILD'S Last NAME: _____

NAME OF PERSON GIVING PERMISSION:
RESPONDENT'S First NAME: _____
RESPONDENT'S Last NAME: _____

TELEPHONE # _____ ***ALTERNATE PHONE #*** _____

BEST TIME & DAY TO CALL: _____

Attempts to call

Day of week	Date	Time	Interviewer ID	Comments
_____	____	____	_____	_____

Appointments to call back:

Today's date/time	Spoke with	Ask for	Callback date/time	Interviewer ID	Notes
_____	_____	_____	_____	_____	_____

Call Disposition Codes

01- Completed interview.
02- Refused interview.
03- Nonworking number.
04- No answer (4-6 tries)
05- Business phone.
06- No eligible respondent at this number
07- No eligible respondent could be reached during time period.
08- Language barrier prevented completion of interview.
09- Interview terminated within questionnaire
10- Line busy (4-6 tries)
11- Selected respondent unable to respond because of physical or mental impairment.

Interviewer ID: _____
Edited By: _____
Date Completed: _____
Final Disposition: _____

Comments:_____

_____

_____

****

Hello. I'm _____ calling from the University of Alabama at Birmingham. May I speak to **(name of person giving permission)**?

a) **IF PERSON DOES NOT LIVE THERE OR IS UNKNOWN, ASK TO VERIFY PHONE NUMBER.**

Is this (205) --- - ----? IF YES, ASK IF (NAME OF CHILD'S PARENT) CAN BE REACHED AT THIS NUMBER. IF NO: Thank you very much, but I seem to have dialed the wrong number. **STOP**

b) **IF PERSON IS NOT AT HOME, ASK FOR A TIME TO CALL BACK AND NOTE ON CALL DISPOSITION CODE AT END OF INTERVIEW.**

TO CORRECT RESPONDENT: I'm calling as a member of a research team at UAB studying services for children with and without special needs in Alabama. If you recall, you agreed to participate in our phone interviews. We are calling about your 2nd grader, **(child's name)**, and wanted to ask some questions about him/her.

The interview will last about 30 minutes. We will be asking you questions about your child's development, behavior and schooling, your family, and your home environment.

I would like to remind you that the information from this interview will remain confidential. You can skip or not answer any questions during the interview or end the interview at any time. There are no right or wrong answers to the questions. Are you still interested in participating in the phone interview?_____ **(Yes/No)**

As you may remember, this is part of a research project and we believe that the information we receive will be helpful for children in Alabama. We want to be sure that we get the best, most accurate information we can, so, I would like to request your permission to have another one of our trained interviewers, _____, listen to your answers on another phone line and record your answers as well. May we have your permission to do this? _____ **(Yes/No)**

If YES, "Hold on and I will get _____ on the line.
If NO, "Thank you, are you still interested in continuing this interview with me?"

CHILD DEMOGRAPHICS & BACKGROUND:

I'd like to begin by asking you some questions about (child's name) and his/her family.

1. Is your child a boy or a girl? Boy .....1 Girl 2

2. How old is **(child's name)**?

3 years old 1
4 years old 2
5 years old 3
6 years old 4
7 years old 5
8 years old 6
Other : _____ . 7

3. What is **(child's name)** date of birth? ___ __ /__ __ /__ __
USE NUMBERS ONLY* FILL IN ALL BLANKS! (month, day, year)

4. Where was **(child's name)** born? (City, State, & County)

City _____
County _____
State _____

5. What is **(child's name)**'s ethnicity/race (or ethnic background)?

Caucasian 1
African-American 2
Hispanic 3
Asian American/Pacific Islander 4
Native American 5
Other, specify _____ 6
Don't Know 8
Refused 9

6. What is your relationship to **(child's name)**? **(Circle response. Do not read list.)**
NOTE: IF THEY SAY 'MOM' CONFIRM IF BIOLOGICAL OR ADOPTIVE MOM.

Biological Mother	1	Biological Father	2
Adoptive Mother	3	Adoptive Father	4
Step Mother	5	Step Father	6
Grand Mother	7	Grand Father	8
Foster Mother	9	Foster Father	10
Aunt	11	Uncle	12
Other Female;	13	Other Male;	14
Specify _____		Specify _____	

7. How long has (**child's name**) lived with you in total? _____ years
if less than 1 year, indicate number in months _____ months

8. Who is (**child's name**)'s primary caregiver? **(Circle response. Do not read list.)**

Biological Mother	1	Biological Father	2
Adoptive Mother	3	Adoptive Father	4
Step Mother	5	Step Father	6
Grand Mother	7	Grand Father	8
Foster Mother	9	Foster Father	10
Aunt	11	Uncle	12
Other Female;	13	Other Male;	14
Specify _____		Specify _____	

9. Who else helps you (or answer to # 8) take care of (**child's name**)?
Circle all that Apply.

Biological Mother	1	Biological Father	2
Adoptive Mother	3	Adoptive Father	4
Step Mother	5	Step Father	6
Grand Mother	7	Grand Father	8
Foster Mother	9	Foster Father	10
Aunt	11	Uncle	12
Other Female;	13	Other Male	14
Specify _____		Specify _____	
No one else	15		

10. What is your present marital status?

Married 1
Never Married 2
Divorced or Separated 3
Widowed 4
Living Together . . . 5

10a. Has your marital status changed since (**child's name**) was born?

Yes 1

If Yes, how has it changed, specify :

_____

_____

No 2

11. How old was **(child's name)**'s biological mother (were you) when **(child's name)** was born?

Record answer and circle response :

18 yrs or less	1
19 - 25 yrs	2
26 - 40 yrs	3
Over 41	4
Don't know	8
Refused	9

12. How old was **(child's name)** biological father when **(child's name)** was born?

Record answer and circle response :

18 yrs or less	1
19 - 25 yrs	2
26 - 40 yrs	3
Over 41	4
Don't know	8
Refused	9

Next, I have some questions about **(child's name)** biological mother and father. First, I will ask about the child's biological mother and then **(child's name)** biological father.

Care giver	13 What is the highest grade of education that (child's name)'s mother/father has completed?	14 What is (child's name)'s mother/father's employment or work status?	15 Was (child's) mother/father ever in Special Education?	16 If so, why was (child's mother/father) in Special Education?
Mother	Did not complete High School Education (less than 12 years) 1 *** What is the highest grade of education you completed ? _____ High School Graduate ..... 2 Complete GED requirements to graduate ..... 3 Some courses at a vocational or technical school or community college, but no Associate's Degree ..... 4 Associates Degree from vocational or technical school or community college ..... 5 Bachelor's degree from 4-year college or univ. ..... 6 Graduate School Degree ..... 7 Don't Know ..... 8 Refused 9	Full-time (40+ hrs/wk) .. 1 Part-time (< 40 hrs/wk) . 2 Retired..... 3 Disabled ..... 4 Unemployed ..... 5 Don't Know ..... 8 Refused 9	Yes ..... 1 No ..... 2 Don't Know ... 8 Refused .. 9	Speech ... 1 Learning .. 2 Behavior .. 3 Social or Emotional. .4 Other .... 5 _____
Father	Did not complete High School Education (less than 12 years) 1 *** What is the highest grade of education you completed ? _____ High School Graduate ..... 2 Complete GED requirements to graduate ..... 3 Some courses at a vocational or technical school or community college, but no Associate's Degree ..... 4 Associates Degree from vocational or technical school or community college ..... 5 Bachelor's degree from 4-year college or univ. ..... 6 Graduate School Degree ..... 7 Don't Know ..... 8 Refused 9	Full-time (40+ hours/wk) 1 Part-time (< 40 hrs/wk) . 2 Retired..... 3 Disabled ..... 4 Unemployed ..... 5 Don't Know ..... 8 Refused 9	Yes ..... 1 No ..... 2 Don't Know ... 8 Refused .. 9	Speech ... 1 Learning .. 2 Behavior .. 3 Social or Emotional. .4 Other ... 5 _____

**** If the primary caretaker is listed (#8) as someone other than the biological mother or father, please ask the following about the primary caregiver****

17. What is the highest grade of education, the **primary caretaker** has completed?

Did not complete High School Education (less than 12 years) 1
*** What is the highest grade of education you completed ? _____
High School Graduate 2
Complete GED requirements to graduate 3
Some courses at a vocational or technical school or community college, but no Associate's Degree 4
Associates Degree from vocational or technical school or community college 5
Bachelor's degree from 4-year college or univ. 6
Graduate School Degree 7
Don't Know 8
Refused 9

18. How many children in the family are in the household, including **(child's name)**? _____

19. How many adults in the family are in the household, including you? _____

20. I will read you a list of family income ranges. Please estimate your total family income range per year? ****IF RESPONDENT ONLY KNOWS PER WEEK OR MONTH, NOTE THE RESPONSE AND PLEASE SEE INCOME SHEET AND CODE ACCORDINGLY.**** _____

$5,000 or less per year 1
$ 5,001 to $10,000 2
$ 10,001 to $14,000 3
$ 14,001 to $ 20,000 4
$ 20,001 to $ 25,000 5
$ 25,001 to $ 30,000 6
$ 30,001 to $ 35,000 7
$ 35,001 to $ 40,000 8
$ 40,001 to $ 45,000 9
$ 45,001 to $ 50,000 10
More than $ 50,000 11
Don't Know 12
Refused 13

21. Think about when **(child's name)** was born. How long was **(child's name)** in the hospital after birth?

(Record parent's exact answer & circle below) _____

Less than 1 week 1
1 - 4 weeks 2
1 - 2 months 3
2 - 6 months 4
6 - 12 months 5
Don't Know.....8 Refused.....9

22. Was **(child's name)** born...

Late ..... 1 - If late, number of Weeks Late child born _____
On- Time 2
Early (premature) ..... 3 - If early, number of weeks early child born _____
Don't Know 4

23. In the first year of his/her life, how would you rate your child's general developmental progress and learning?

More advanced than other children his/her age 1
Same as other children his/her age 2
Less advanced than other children his/her age 3
A great deal below other children his/her age 4
Don't Know.....8 Refused.....9

23a. Did **(child's name)** ever receive any type of early intervention or preschool special services or any help for a special need prior to beginning public school?

Yes 1
No 2
Other _____ 3
Don't Know 8
Refused 9

24. I will read a list of problems young children may have. Please tell me whether or not your child **EVER has** had any of these problems. **(Read all problems and mark yes/no. Then read questions 24-26.)**

Problem	24 Yes (1)	24 No (2)	25 When was (type of problem) first noticed?	26. Did (child's name) receive any of the following types of help for this problem? *****READ LIST..... Mark all that apply.*****	If other type of help specify
Physical Problem	1	2	During Pregnancy.. 1 At time of Birth .... 2 Less than 1 year .... 3 1- less than 3 years . 4 3- less than 6 years . 5 6-8 years ..... 6 Don't Know.....8 Refused.....9	Early Intervention services or help for a special need (prior to age 3) ..... 1 Preschool special services or help for a special need (3-5 years old) ..... 2 Special Education services (5 years and older) ..... 3 Counseling ..... 4 Written information ..... 5 Help wanted but not received ..... 6 No help needed or received ..... 7 Other (Specify in next column) **RECORD ALL INFO* . 8	
Behavior Problem - (such as child being unable to control behavior or sit still)	1	2	During Pregnancy.. 1 At time of Birth .... 2 Less than 1 year .... 3 1- less than 3 years . 4 3- less than 6 years . 5 6-8 years ..... 6 Don't Know.....8 Refused.....9	Early Intervention services or help for a special need (prior to age 3) ..... 1 Preschool special services or help for a special need (3-5 years old) ..... 2 Special Education services (5 years and older) ..... 3 Counseling ..... 4 Written information ..... 5 Help wanted but not received ..... 6 No help needed or received ..... 7 Other (Specify in next column) **RECORD ALL INFO* . 8	
Speech Problem - (such as child having a speech delay or adults being unable to understand child	1	2	During Pregnancy.. 1 At time of Birth .... 2 Less than 1 year .... 3 1- less than 3 years . 4 3- less than 6 years . 5 6-8 years ..... 6 Don't Know.....8 Refused.....9	Early Intervention services or help for a special need (prior to age 3) ..... 1 Preschool special services or help for a special need (3-5 years old) ..... 2 Special Education services (5 years and older) ..... 3 Counseling ..... 4 Written information ..... 5 Help wanted but not received ..... 6 No help needed or received ..... 7 Other (Specify in next column) **RECORD ALL INFO* . 8	
Hearing Problem	1	2	During Pregnancy.. 1 At time of Birth .... 2 Less than 1 year .... 3 1- less than 3 years . 4 3- less than 6 years . 5 6-8 years ..... 6 Don't Know.....8 Refused.....9	Early Intervention services or help for a special need (prior to age 3) ..... 1 Preschool special services or help for a special need (3-5 years old) ..... 2 Special Education services (5 years and older) ..... 3 Counseling ..... 4 Written information ..... 5 Help wanted but not received ..... 6 No help needed or received ..... 7 Other (Specify in next column) **RECORD ALL INFO* . 8	

Problem	24 Yes (1)	No (2)	25 When was (type of problem) first noticed?	26 Did (child's name) receive any of the following types of help for this problem? *****READ LIST..... Mark all that apply*****	If other type of help specify
Emotional Problem - such as not getting along with other children or adults	1	2	During Pregnancy.. 1 At time of Birth .... 2 Less than 1 year .... 3 1- less than 3 years . 4 3- less than 6 years . 5 6-8 years ..... 6 Don't Know.....8 Refused.....9	Early Intervention services or help for a special need (prior to age 3) ..... 1 Preschool special services or help for a special need (3-5 years old) ..... 2 Special Education services (5 years and older) ..... 3 Counseling ..... 4 Written information ..... 5 Help wanted but not received ..... 6 No help needed or received ..... 7 Other (Specify in next column) **RECORD ALL INFO* . 8	
Learning Problem - such as learning more slowly than other children or having difficulty learning	1	2	During Pregnancy.. 1 At time of Birth .... 2 Less than 1 year .... 3 1- less than 3 years . 4 3- less than 6 years . 5 6-8 years ..... 6 Don't Know.....8 Refused.....9	Early Intervention services or help for a special need (prior to age 3) ..... 1 Preschool special services or help for a special need (3-5 years old) ..... 2 Special Education services (5 years and older) ..... 3 Counseling ..... 4 Written information ..... 5 Help wanted but not received ..... 6 No help needed or received ..... 7 Other (Specify in next column) **RECORD ALL INFO* . 8	
Other Problem (specify) ..Write in response : _____ _____ _____ _____ _____ _____ _____ _____	1	2	During Pregnancy.. 1 At time of Birth .... 2 Less than 1 year .... 3 1- less than 3 years . 4 3- less than 6 years . 5 6-8 years ..... 6 Don't Know.....8 Refused.....9	Early Intervention services or help for a special need (prior to age 3) ..... 1 Preschool special services or help for a special need (3-5 years old) ..... 2 Special Education services (5 years and older) ..... 3 Counseling ..... 4 Written information ..... 5 Help wanted but not received ..... 6 No help needed or received ..... 7 Other (Specify in next column) **RECORD ALL INFO* . 8	

Note: IF RESPONDENT REPLIED **YES** TO ANY INVOLVEMENT IN SPECIAL SERVICES BEFORE AGE 5 in questions 23a - 26 then, ASK **QUESTIONS 27 - 32.**
IF NOT SKIP TO PAGE 11, QUESTION 33.

NEXT, I'd like to ask you about the early intervention or preschool services or special help (child's name) was involved in before he or she entered public school (kindergarten).

27. Who first told you about the programs or services for **(child's name)**?

Self.....1
Relative.....2
Nurse.....3
Spouse.....4
Doctor.....5
Friend 6
School..... 7
Other, specify _____.....8
Don't Know 9
Refused 10

28. How old was **(child's name)** when he/she started attending a program or receiving services?.....Record age and then circle appropriate response: _____

Less than 12 mos.....1
1 years old to less than 2 years old....2
2 years old to less than 3 years.....3
3 years old to less than 4 years.....4
4 years old to less than 5 years old 5
5 years old and older 6
Don't Know 8
Refused 9

29. For how many years did **(child's name)** receive early intervention services and/or preschool special services or program?

Less than 12 mos.....1
1 years to less than 2 years 2
2 years to less than 3 years.....3
3 years to less than 4 years.....4
4 years to less than 5 years 5
5 years or more 6
Don't Know 8
Refused 9

30. Where did **(child's name) usually** receive these services? *******READ LIST*******

At home.....1
At a Child Development or Intervention Center (not at home) 2
Combination of home-based and center-based 3
Other , specify _____ 4
Don't Know.....8 Refused 9

31. How many **days a week** did **(child's name)** usually receive these services?

1 day/week.....1
2 days/week.....2
3 days/week.....3
4 days/week 4
5 days/week 5
Other, specify _____.....6

32. How many hours **a day** did (child's name) usually receive these services?
Record exact response _____ hours per day, then mark answer below:

1 hour per day or less 1
Between 1 and 2 hours/ day.....2
Between 3 and 4 hours/ day.....3
Don't Know.....8
Between 5 and 6 hours/ day.....4
Between 7 and 8 hours/ day.....5
Other, specify _____...6
Refused 9

We are also interested in (child's name) special education program.

33. I will read you a list of common reasons children receive special education services. Does **(child's name)**'s school say that any of these reasons is why he/she is receiving special education services? **(Read List -- Circle all that apply.)**

Learning Disability 1
Mental Retardation 2
Speech/Language Impairment or Problem 3
Autism 4
Emotional Conflict or Problem 5
Hearing Impairment 6
Orthopedically Impaired 7
Traumatic Brain Injury 8
Multi-Disabled 9
Other Health Impairment 10
Other, Specify_____ ..11
None of the Above .....12 Don't know or understand 13

34. (If **"None of the above"** or **"Don't Know or Understand** "to the above) - Ask: Why do you think **(child's name)** is receiving special education services?

_____

_____

_____

35. When was the decision made to place **(child's name)** in the special education program?

Preschool 1
Kindergarten 2
First Grade 3
Second Grade 4
Don't know 8
Refused 9

36. What type of classroom is **(child's name)** presently in?

Regular Classroom

a. **For Full day** (In a class of children without disabilities; with help of aide) . 1
b. **With Outside services** (In class of children without disabilities, but receives services during the week outside of the classroom) 2
c. **For Partial Day** (Child attends part of the day in classroom of children without disabilities and partial day in classroom of children with disabilities) . 3

Self - Contained Classroom (Child in classroom with other children with disabilities only) . . 4
Other _____ 5
Don't know.....8 Refused.....9

37. Has your child ever been retained or repeated a grade? No 0
Yes 1

38. If Yes, What Grade did **(child's name)** repeat: _____* USE NUMBERS*

Please answer <u>all</u> of the following questions about how your child's time is spent and some of the activities of your family. I will read possible responses for each question. You can choose more than one response. ****** *READ ALL RESPONSES*******

39. a) Do you get any magazines in the mail?

NO .... 0 * **IF NO, SKIP TO 40**
YES 1

		No	Yes
b) If yes, what kind?	News magazines	0	1
	Home and Family magazines	0	1
	Children's magazines	0	1
	Other	0	1

40. Does (**child's name**) have a toy box or other special place where he/she keeps his/her toys?

NO 0
YES 1

41. How many children's books does your family own?

0 to 2 1
3 to 9 2
10 or more 3

42. How many books do you have besides children's books?

0 to 9 1
10 to 20 2
20 or more 3

42a. Where do you keep the books besides children's books?

Packed In boxes 1
On a bookcase 2
Other (explain) _____ 3

43. How often does someone take (**child's name**) into a grocery store?

At least once a week 1
At least twice a month 2
At least once a month 3
Hardly ever 4

44. About how many times in the past week did you spank (**child's name**)?

	<u>No</u>	<u>Yes</u>
Not at all or Once	0	1
More than once	0	1

45. Do you have a T.V.?

NO ..... 0 *** IF NO, SKIP TO 46**
YES 1

45a. How many hours per day is the T.V. on?
Record Exact answer: _____

46. How often does someone read stories to (**child's name**)?

Hardly ever 1
At least once a week 2
At least three times a week 3
At least five times a week 4

47. Do you ever sing to or with (**child's name**) when he/she is nearby?

NO 0
YES 1

48. Does (**child's name**) put away his/her toys by himself/herself most of the time?

NO 0
YES 1

49. Is (**child's name**) allowed to walk or ride his/her bicycle by himself/herself to the house of a friend or relative?

NO 0
YES 1

50. What do you do with (**child's name**) art work?

Let him/her keep it 1
Put it away 2
Hang it somewhere in the house 3
Throw it away shortly after looking at it 4

51. What would you say if (**child's name**) said, "Look at that big truck".

_____
_____
_____

***Note: At end of interview, code respondent's answer"**

A response like 'I would tell him/her the color of the truck" 0

Direct quote of a response to a child, such as "Yes, it is a red truck.: 1

52. Which of the following do you usually do when a friend is visiting you in your home and (**child's name**) has nothing to do?

	No	Yes
Suggest something for him/her to do	0	1
Offer him/her a toy	0	1
Give him/her a cookie or something to eat	0	1
Put him/her to bed for a nap	0	1
Play with him/her	0	1
None of the above	0	1

53. How often does (**child's name**) eat a meal at the table with both mother and father (or other adult male)?

Never 1
At least once a month 2
At least once a week 3
At least twice a week 4
At least 3 or 4 times a week 5
At least once a day 6

54. How often does (**child's name**) spend time playing or "working" with his/her father (or other adult male)?

Never 1
At least once a month 2
At least once a week 3
At least twice a week 4
At least 4 times a week 5

55. How often does someone get a chance to take (**child's name**) out of the house for an outing (shopping, park, zoo, restaurant, museum, car trip, library, etc.)?

At least 6 times a year (or every 2 months) 1
At least once a month 2
At least twice a month 3
At least once a week 4

56. Which things have you (or other adult or older child) helped or are helping (**child's name**) to learn: ** Mark all that Apply.

	No	Yes
Colors (like naming colors)	0	1
Alphabet	0	1
Numbers	0	1
Understanding of time (Like now/later or morning/afternoon)	0	1
Shapes (like drawing circles or squares)	0	1
Reading new words or writing his/her name	0	1

57. Has (**child's name**) learned any songs, prayers, or nursery rhymes?

NO ..... 0 *** IF NO, SKIP TO 58**
YES 1

57a. If yes, where did s/he learn them?

At day care or preschool 1
From a sister or brother 2
At church or Sunday School 3
From mother or father 4
From television 5
Other, specify _____ .. 6

58. It is 30 minutes before dinner and (**child's name**) is hungry. Most of the time you would:

Give him/her a snack 0
Have him/her wait for dinner 1

59. Which items do you sometimes let (**child's name**) choose for himself/herself?

	No	Yes
Part of what to have for breakfast or lunch	0	1
Favorite foods in the grocery store (fruit, cereal, cookies, etc.)	0	1
The clothes he/she wants to put on	0	1
None of the above	0	1

60. What would you do if (**child's name**) got angry and hit you?

	No	Yes
Hit him/her to show him/her it hurts	0	1
Send him/her to his/her room	0	1
Spank him/her	0	1
Talk to him/her	0	1
Ignore it	0	1

61. Do you have any pets?
NO 0
YES 1

62. Do you have any plants in your house?
NO 0
YES 1

63. Which of the following statements I read best describes your neighborhood:

It is not as clean as you would like it 1
The houses are not well cared for 2
It is well cared for 3
It is well cared for and attractive 4

64. How many bedrooms does your house or apartment have? _____ bedrooms

64a. How many people are living in your house or apartment? _____ people

65. Do you occasionally try new recipes that you find in the newspaper or magazines?

NO 0
YES 1

66. Is anyone in the family presently taking a class in school at the college level?

NO 0
YES 1

67. Who buys the groceries for the family? For each response, do they buy them sometimes or often?

	Never	Sometimes	Often
Mother	2	0	1
Father	2	0	1
Grandparent	2	0	1
Older Child	2	0	1
Other: _____			

68. Most of the decisions about how the family income is to be spent (or financial decisions within the household) are made by: Mark all that Apply

	No	Yes
Mother	0	1
Father	0	1
Grandparent	0	1
Friend	0	1

69. How often do you and (**child's name**) get a chance to play together (like pretend games, dolls, house, cars and trucks, or table games)?

	No	Yes
Hardly ever; too young	0	1
At least once a week	0	1
At least 3-4 times a week	0	1
Everyday	0	1

70. Do you have any friends or relatives with children about the same age as **(child's name)**?

NO 0
YES 1

71. When **(child's name)** asks if he/she can do something you think he/she is too young to do, would you be more likely to say:

	No	Yes
No, I don't want you to	0	1
No.	0	1
Not now	0	1
No. You're too young now but when you're older you'll be able to do it.	0	1
Other : _____		

72. What would happen if **(child's name)** spilled his/her milk?

	No	Yes
He/she would be spanked	0	1
He/she would have to clean it up	0	1
Someone else would clean it up	0	1
He/she would be sent to his/her room	0	1
Other : _____		

For each of the items I will read next, please think about **(child's name) present behavior.** Decide **how often (child's name)** does the behavior described. You may answer **never, sometimes,** or **very often.**

SOCIAL SKILLS	HOW OFTEN? Never	Sometimes	Very Often
1. Uses free time at home in an acceptable way.	0	1	2
2. Keeps room clean and neat without being reminded	0	1	2
3. Speaks in an appropriate tone of voice at home.	0	1	2
4. Joins group activities without being told to.	0	1	2
5. Introduces herself or himself to new people without being told.	0	1	2
6. Responds appropriately when hit or pushed by other children.	0	1	2
7. Asks sales clerks for information or assistance.	0	1	2
8. Attends to speakers at meetings such as in church or youth groups.	0	1	2
9. Politely refuses unreasonable requests from others.	0	1	2
10. Invites others to your home.	0	1	2

	HOW OFTEN?		
SOCIAL SKILLS	**Never**	**Sometimes**	**Very Often**
11. Congratulates family members on accomplishments.	0	1	2
12. Makes friends easily.	0	1	2
13. Shows interest in a variety of things.	0	1	2
14. Avoids situations that are likely to result in trouble.	0	1	2
15. Puts away toys or other household property.	0	1	2
16. Volunteers to help family members with tasks.	0	1	2
17. Receives criticism well.	0	1	2
18. Answers the phone appropriately.	0	1	2
19. Helps you with household tasks without being asked.	0	1	2
20. Appropriately questions household rules that may be unfair.	0	1	2
21. Attempts household tasks before asking for your help.	0	1	2
22. Controls temper when arguing with other children	0	1	2
23. Is liked by others.	0	1	2
24. Starts conversations rather than waiting for others to talk first.	0	1	2
25. Ends disagreements with you calmly.	0	1	2
26. Controls temper in conflict situations with you.	0	1	2
27. Gives compliments to friends or other children in the family.	0	1	2
28. Completes household tasks within a reasonable time.	0	1	2
29. Asks permission before using another family member's property.	0	1	2
30. Is self-confident in social situations such as parties or group outings.	0	1	2
31. Requests permission before leaving the house.	0	1	2
32. Responds appropriately to teasing from friends or relatives of his or her own age.	0	1	2
33. Uses time appropriately while waiting for your help with homework or some other task.	0	1	2
34. Accepts friends' ideas for playing.	0	1	2
35. Easily changes from one activity to another.	0	1	2
36. Cooperates with family members without being asked to do so.	0	1	2
37. Acknowledges compliments or praise from friends.	0	1	2

HOW OFTEN?

SOCIAL SKILLS	Never	Sometimes	Very Often
38. Reports accidents to appropriate persons.	0	1	2
39. Fights with others.	0	1	2
40. Acts sad or depressed	0	1	2
41. Appears lonely.	0	1	2
42. Has low self-esteem.	0	1	2
43. Threatens or bullies others.	0	1	2
44. Disturbs ongoing activities.	0	1	2
45. Shows anxiety about being with a group of children	0	1	2
46. Argues with others	0	1	2
47. Fidgets or moves excessively.	0	1	2
48. Disobeys rules or requests.	0	1	2
49. Talks back to adults when corrected.	0	1	2
50. Acts impulsively.	0	1	2
51. Doesn't listen to what others say.	0	1	2
52. Is easily embarrassed.	0	1	2
53. Is easily distracted.	0	1	2
54. Gets angry easily.	0	1	2
55. Has temper tantrums.	0	1	2

These are all the questions that I have for you.

Do you have any final comments about (child's name) or his/her being in special education?

_____

_____

_____

Do you have the name and phone number of someone to call at the school if you have any questions or concerns about **(child's name)**? If not, a number you can call if you have questions about **(child's name)** is 583-4600.

Thank you very much for taking time to answer these questions. You have given me some important information that will be used to help children throughout Alabama.

_____

*****ONLY READ BELOW IF PARENTS ASK FOR RESULTS OR TO TALK TO SOMEONE FURTHER ABOUT THE STUDY!**

NOTE: If parents (interviewee) request information/results/outcome from study, inform them that at the end of the study, we will be happy to send them a summary of results across all interviews.

Record address:

_____

_____

_____

If parents would like a name and number of a researcher at UAB to contact if you have further questions about this interview, they can contact **Sam Cluett at 934-5461** and she will be happy to assist you.

Appendix
D

Case Control Analysis

Mental Retardation

Apgar Score at 5 Minutes less than 7	**6.395***
Maternal Education less than High School	**3.948***

All odds ratios derived from a single logistic model which contained seven variables: gestational age of child, gender of child, birthweight, Apgar scores, education of mother, age of mother.

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